

Webinar: Improving health services for disabled children

- 1) Health services supporting disabled children
- 2) Examples of service improvement - working with parent carer forums
- 3) SEND reforms - opportunity to improve, it will take time

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www.cafamily.org.uk/parentcarerparticipation

Child A : Physical and/or Learning Disability

Often identified at birth or soon after birth e.g. cerebral palsy, Down syndrome

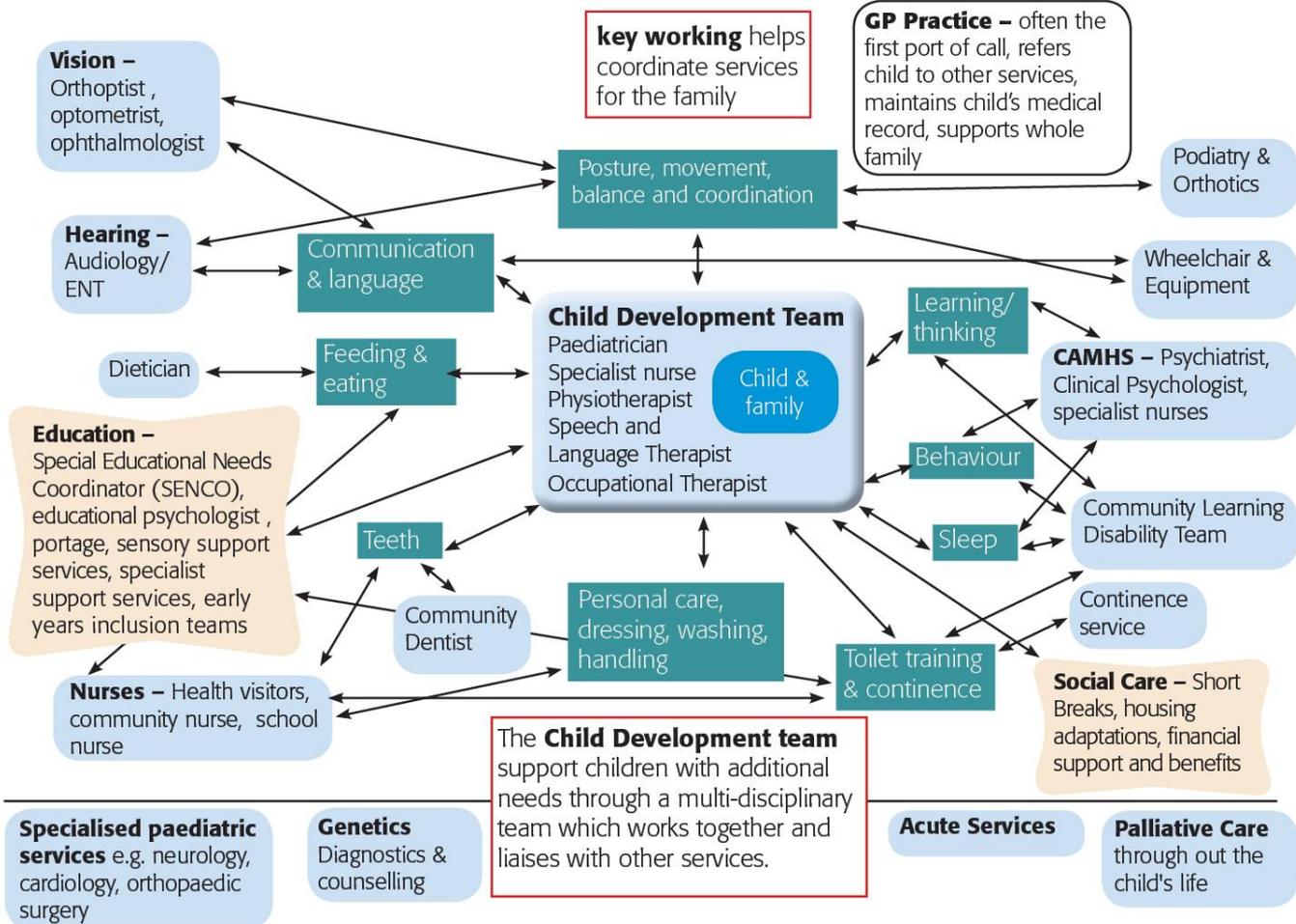
Depending on disability might need support around:

- Feeding/ eating
- Speech & Communication
- Mobility & fine motor skills
- Learning – including self care

Also various health needs, might be eligible for continuing care but not all will be complex

Who in health might be involved in supporting this child?

Health Services



Key workers and key working approaches

- act as a single point of contact for the family and coordinate the family's support
- key working is recommended in NICE autism guidelines & the SEN Code of Practice

might be called lead professional care coordinator, family support worker, early support worker

For more information on key working see

<http://www.councilfordisabledchildren.org.uk/earllysupport>

Child development team

- Multidisciplinary team - led by paediatrician
- Includes physiotherapists, occupational and speech and language therapists – might require input from psychologists / psychiatrists
- The team consider the different areas of development, agrees priorities and devise interventions to help the child develop skills
- Interventions can be delivered by parents / early years / schools
- Most effective in the first few years while the brain still developing

For more information read:

GP practice guide: supporting disabled children and young people

www.cafamily.org.uk/healthprofessionals

Team Around the Child Approach (TAC)

Example

- Family attend regular review meeting – report mealtimes are extremely difficult – the family think child is frustrated as she cannot feed herself.
- Team agrees to prioritise supporting child to feed herself over next few months
- Physiotherapist devise exercises to help child improve arm/hand coordination so child can learn to self feed
- Speech and language therapists provided advice on food and fluid consistencies
- Occupational therapist provide help with seating and equipment

Child B: Developmental delay age 2 to 3

Child identified as possible development delay (might be health visitor, early years settings, parent, school)

Child referred for assessment to child development team

Assessment might require input from therapists, psychiatrists

This might *eventually* lead to diagnosis – e.g. learning disability, Autism Spectrum Disorder. Many children with additional needs never get a name for their medical condition

NICE guidelines autism = 18 weeks from referral to completed assessment - in some places it can take two years

Clinical pathways important - If assessment delayed – getting support for child is delayed

Child B: Developmental delay age 2 to 3

might have difficulty with:

Speech & communication - including interacting with others

Coordination and fine motor skills

Learning new skills– e.g. personal self care, continence,

Sensory overload – oversensitive to sound, textures, bright colours

Feeding/ eating - refusing certain textures of food

Poor sleepers – disrupting the entire family

High risk of developing **behaviour that challenges**

High risk of developing **mental health issues**

Without early support problems become entrenched and are more difficult to reverse

Who in health might be involved in supporting this child?

Child B: Developmental delay

Once assessed, child likely to be discharged by child development team with letter sent to education /social care

- Schools required to use their budget to provide support for children with additional or special educational needs (was School Action & School Action Plus)
- If child needs cannot be met by school (and LA top up funding) then statutory assessment (leading to SEN statement)

Most parents not given strategies to help managing behaviour, sleep, toilet training, feeding/eating

NICE guidelines managing autism say child should be referred to autism team for support.

Child C: aged 5 plus

Child identified by school – problems communication, learning, social interaction, behaviour

Refer to paediatrician / CAMHS for assessment (CDT often only sees 0-5)

This *might* lead to diagnosis ASD, Learning Disability, ADHD or mental health issues

Contact a Family help line frequently hearing about CAMHS refusing referrals to carry out assessments as children not 'bad' enough

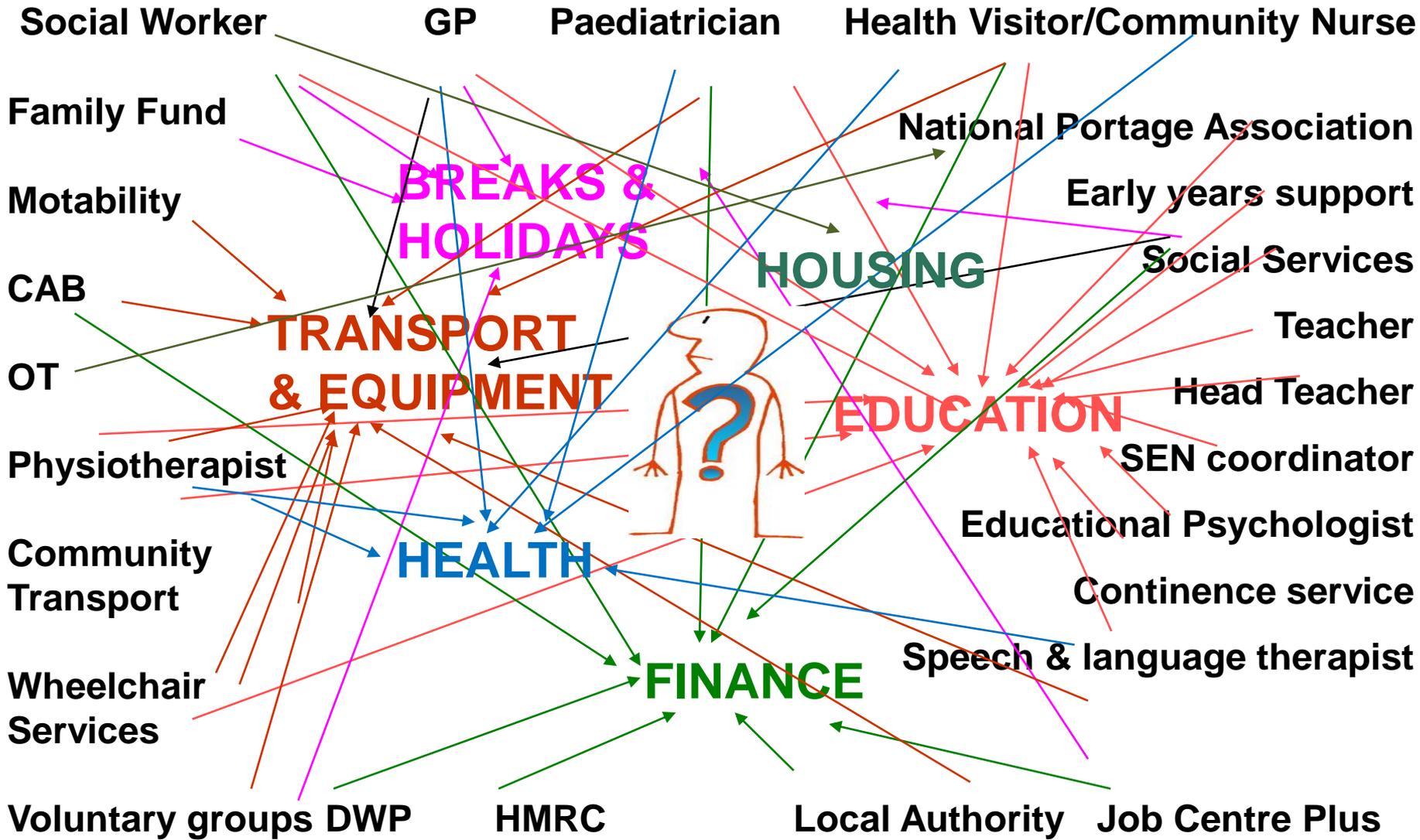
Child left in limbo – no assessment – no support

Improving services



‘If you want to know how well a pair of shoes fit you ask the person wearing them not the person who made them.’

Anon



Improving services

Development of parent carer forums

Parent carers came together as they saw the shortfalls in the system and wanted to make it work better

A parent carer forum work with local authorities, education, health and other providers to make sure the services they plan and deliver meet the needs of disabled children and families.

Parent carer forums are now functioning in most local authority areas – thanks to funding support from the Department for Education

Read more on www.cafamily.org.uk/parent-carer-forums

The National Network of Parent Carer Forums work as a network of forums at regional and national level to participate and influence nationally as local forums do locally

See www.nnpf.org.uk

Improving services

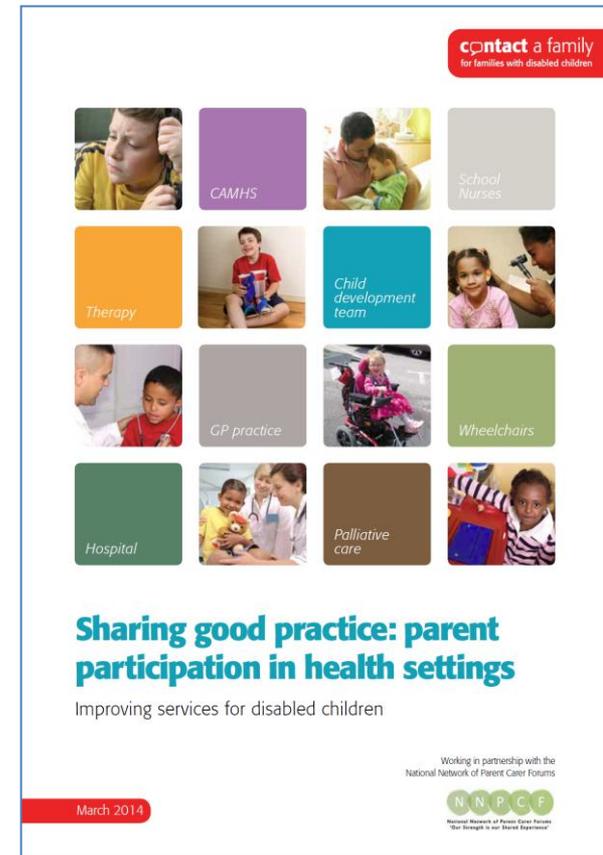
Sharing good practice in health settings

Illustrates the benefits of working with parents and parent carer forums

Printed copies available on request-email Natalie.Adams@cafamily.org.uk

Examples from different settings, provided solutions to problems reported by many families

Download electronic version from www.cafamily.org.uk/pcp/health



Kirklees parents– influencing CAMHS

Background

- Parent dissatisfaction with CAMHS service for disabled children
- Commissioner wanting to know more

New tier 3 service specification for children with learning disabilities

includes learning disability nurse and support staff working alongside psychiatrists and psychologists – focusing on providing holistic support coordinated with other local services

Structured Focus workshop

commissioner, asked parents:

- what causes child to be stressed?
- impact on child & families lives?
- their experience of CAMHS?
- what would help?

New tier 2 service specification for children with learning disabilities

Includes support to help school understand and manage child's emotional and behaviour needs

Support for parents, through parent groups, to help manage child's emotional and behaviour needs

Hampshire– Therapies

Background

- Parents reported problems
- Postcode lottery, long waits, therapists in different settings, poor coordination, children not receiving regular reviews, complaints

What happened next

- Forum approached Overview & Scrutiny Committee
- Hampshire county council set up project board – invited therapists and parent representatives

New multi-disciplinary service

- Service provided from two centres
- Telephone triage
- Children seen in set waiting time & receive regular reviews
- No longer a postcode lottery
- Families happier with service

- Project board investigated & proposed service model used in Wiltshire
- Commissioner persuaded 5 CCGs to jointly commission one service for whole county
- Commissioner worked with project board to develop new specification and go through tender process

Leeds – behaviour, sleep, toilet training

Background

- Forum realised parents wanted support on these issues
- Forum approached paediatrician – who did not have enough capacity to help

What happened next

- Paediatrician set up a working group – inviting community services, parent carer forum & other agencies to try to find solution

- Families helped on these issues by specialist nurses
- Paediatrician time freed up for clinical work
- Paediatricians holds some clinics in special school
- Children not being taken out of school for appointments

- Discovered school nurses in special schools had skill and knowledge to help and were already informally helping some parents
- School nurses agreed to provide a service one day a week, parent ring for appointment
- Forum let parents know about service

Improving services

Parent carer forums

can help commissioners

Needs assessment – input on how service is experienced, including shortfalls

Specification – explain what needs to change to make it work

Procurement - help assess how well providers understand the type of support needed

Contract management – help monitor service by providing feedback of service

More success stories

www.cafamily.org.uk/pcp/success

Children & Families Act 2014 - implemented from September 2014

Local offer

New duty for joint commissioning

Designated medical officer

EHC plans

Participation



Statutory Guidance [Special educational needs and disability code of practice 0 to 25 years](#)

July 2014, Ref DFE-00205-2013, www.gov.uk

Local offer

Local authorities must produce a 'local offer' of services it expects to be available for disabled children and young people up to 25 years

Services provided by education, health, social care and voluntary sector

Local Authorities and CCGs have to be clear about:

- eligibility and how to access service
- who is responsible for providing what

Local authorities and CCG's also have a duty to involve parent carers and young people in decisions about these services

Local offer - could help prevent children & families falling through gaps

Provide families with information about support they are not aware of, which could prevent disabled children needing more expensive services

- **Dental care** – many children cannot access dentists, community dentists can prevent them later needing dental surgery
- **Toilet training** – helping families toilet train disabled children to be continent can reduce costs for health & education
- **Sleep** – improve health outcomes for whole family
- **Behaviour** - providing families with positive behaviour strategies, minimising challenging behaviour, less need for CAMHS, residential settings

Joint Commissioning - How services are commissioned has consequences for other agencies

Examples

If health will not provide disabled children with electric wheelchair with risers, then education have to spend more money on providing a support assistant to push the child around the school and adapting classrooms

If disabled children are not able to access short breaks, then families stress levels increase which can lead to an increased demand for health services.

If disabled children are not supported in school re communication, behaviour & social skills, this can lead to more children needing a referral to CAMHS

It makes sense to do joint commissioning

SEND reforms

Designated Medical / Clinical Officer for SEN

Clinical commissioning groups to appoint a designated Medical/Clinical Officer for SEN to coordinate and support the implementation of the SEND reforms including EHC plans

- work strategically across health, social care and education
- coordinate the role of the health in EHC needs assessment
- build relations with local commissioners in joint arrangements for SEN
- encourage joint working through partnership arrangements and pooled budgets

Might find it helpful to review clinical pathways, checking for bottlenecks delaying children being assessed and appropriate support being provided

Who funds what can be confusing

NHS provides equipment for a child's nursing or medical needs

LA children's services provides equipment for daily living & social care

Education provide equipment for aids to support a child's learning

This can lead to disagreements, causing delays in the child getting support, or situation where child has communication aid at school but is not able to use at home.

Pooling budgets can prevent this and save a lot of time in arguments

SEND reforms

EHC Plans

Previously	New system
Statements (0 to 18) and learning disability assessments	EHC needs assessment & plans (0 to 25)
School Action & Action Plus	SEN support

The bill includes a duty on local authorities to introduce:

Education, health and care (EHC) plans

replace the statement of special educational needs

extend to age 25 for children who remain in training or education

SEND reforms

EHC Plans – health assessment will be more focused on support needs of child

Health conditions	Feeding
Mobility and posture	Continence
Hand function and personal care	Social communication and relationships
Communication, speech and language	Behaviour and emotions
Hearing	Vision
Sleep	Pain

More thorough assessments than previously provided by health to support statement process

SEND reforms

EHC Plans

Step 1: Understanding the child or young person's needs and aspirations

Sections

A The views, interests and aspirations of the child and their parents, or of the young person

B The child or young person's special educational needs identified through the **EHC assessment**

C The child or young person's health needs

D The child or young person's social care needs

Health assessments can identify SEN support needs
e.g. hand function, personal care, communication ,
social relationships

SEND reforms

EHC Plans

Step 2: Agreeing outcomes for the child or young person and how to help them achieve them

Section E

Developed using information in sections A,B,C,D

Range of outcomes covering education, health and care

What steps will be taken to help child meet the outcomes and when they should be achieved

How progress will be monitored and reviewed

SEND reforms

EHC Plans

Step 3: Agree who will provide what to help cyp meet outcome

Sections

- F** Education provision - might include SLT, toilet training, life skills
- G** Health provision - might include hearing aids, physiotherapy, occupational therapy, continence products
- H** Social care provision - might include access to short breaks, holidays
- I** Placement – nursery, school or college
- J** Personal Budget - being used to fund provision

EHC plan reviewed - at least every year

IPSEA has created a [checklist](#) that sets out what legally must be included as a minimum in any Education, Health and Care Plan

Worked [examples](#) from Portsmouth & Southampton on SEND pathfinder website at www.sendpathfinder.co.uk

SEND reforms

Transitional period

From Sept 2014: Priority new entrants, LDA's & young people moving into further education or training

All children and young people with existing statements to be transferred by April 2018

Gradually more and more children & young people will be requiring EHC assessments, EHC plans and personal budgets

Implementing a new 0 to 25 special needs system:
LAs and partners Duties and timescales
-what you must do and when, July 2014
DFE-00478-2014 , www.gov.uk

SEND reforms

Participation of parents and young people

Can lead to a better fit between families' needs and the services provided

Parent carer forums have been established in most local areas and many already working with the local authority on implementing the SEND reforms.

They can help health identify shortfalls in health services and work with you to find solutions

See www.cafamily.org.uk/parent-carer-forums

& contact details for forums www.nnpcof.org.uk

SEND reforms

Everyone working together

- **At individual level** – how best they can support the child
- **At strategic level** – how can we make most effective use of resources

Requires

- **Dialogue** between the ALL the people involved, including family
- **Listening** to and understanding each others perspective
- **Working together** to find & implement solutions
- **Monitoring** to make sure solutions work